## 104TH CONGRESS 1ST SESSION

## H. R. 835

To amend the Public Health Service Act to provide for expanding and intensifying activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases with respect to lupus.

## IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 6, 1995

Mrs. Meek of Florida introduced the following bill; which was referred to the Committee on Commerce

## A BILL

- To amend the Public Health Service Act to provide for expanding and intensifying activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases with respect to lupus.
  - 1 Be it enacted by the Senate and House of Representa-
  - 2 tives of the United States of America in Congress assembled,
  - 3 **SECTION 1. SHORT TITLE.**
  - 4 This Act may be cited as the "Lupus Research
  - 5 Amendments of 1995".
  - 6 SEC. 2. FINDINGS.
  - 7 The Congress finds that—

- (1) lupus is a serious, complex, inflammatory,
  autoimmune disease of particular concern to women;
  - (2) lupus affects women 9 times more often than men:
  - (3) there are 3 main types of lupus: systemic lupus, a serious form of the disease that affects many parts of the body; discoid lupus, a form of the disease that affects mainly the skin; and drug-induced lupus caused by certain medications;
  - (4) lupus can be fatal if not detected and treated early;
  - (5) the disease can simultaneously affect various areas of the body, such as the skin, joints, kidneys, and brain, and can be difficult to diagnose because the symptoms of lupus are similar to those of many other diseases;
  - (6) lupus disproportionately affects African-American women, as the prevalence of the disease among such women is 3 times the prevalence among white women, and an estimated 1 in 250 African-American women between the ages of 15 and 65 develops the disease;
  - (7) it has been estimated that over 500,000 Americans have been diagnosed with the disease, and that many more have undiagnosed cases;

1	(8) current treatments for the disease can be
2	effective, but may lead to damaging side effects; and
3	(9) many victims of the disease suffer debilitat-
4	ing pain and fatigue, making it difficult to maintain
5	employment and lead normal lives.
6	SEC. 3. EXPANSION AND INTENSIFICATION OF ACTIVITIES
7	REGARDING LUPUS.
8	Subpart 4 of part C of title IV of the Public Health
9	Service Act (42 U.S.C. 285d et seq.) is amended by insert-
10	ing after section 441 the following section:
11	"LUPUS
12	"Sec. 441A. (a) In General.—The Director of the
13	Institute shall expand and intensify research and related
14	activities of the Institute with respect to lupus.
15	"(b) Coordination With Other Institutes.—
16	The Director of the Institute shall coordinate the activities
17	of the Director under subsection (a) with similar activities
18	conducted by the other national research institutes and
19	agencies of the National Institutes of Health to the extent
20	that such Institutes and agencies have responsibilities that
21	are related to lupus.
22	"(c) Programs for Lupus.—In carrying out sub-
23	section (a), the Director of the Institute shall conduct or
24	support research to expand the understanding of the

25 causes of, and to find a cure for, lupus. Activities under

such subsection shall include conducting and supporting the following: 2 3 "(1) Research to determine the reasons underlying the elevated prevalence of lupus in women, including African-American women. 5 "(2) Basic research concerning the etiology and 6 7 causes of the disease. 8 "(3) Epidemiological studies to address the frequency and natural history of the disease and the 9 differences among the sexes and among racial and 10 11 ethnic groups with respect to the disease. "(4) The development of improved screening 12 techniques. 13 "(5) Clinical research for the development and 14 15 evaluation of new treatments, including new biologi-16 cal agents. 17 "(6) Information and education programs for 18 health care professionals and the public. 19 "(d) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated \$20,000,000 for fiscal year 1995, and 21 such sums as may be necessary for each of the fiscal years 1996 and 1997. The authorization of appropriations es-

tablished in the preceding sentence is in addition to any

- $1 \ \ other \ authorization \ of \ appropriations \ that \ is \ available \ for$
- 2 such purpose.".

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